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Case conference

The limits of informed consent

The patient, a 59-year-old man, was referred to a psychiatric hospital with what appeared initially to be the signs and symptoms of mental disorder. In hospital a lesion of the brain was diagnosed and surgery was proposed to relieve the condition. The patient, however, during this and subsequent admissions to hospital, refused operation. His refusal to consent was regarded as valid as he seemed to have good insight into his condition. Finally, under section 26 of the Mental Health Act, he was treated surgically. Unfortunately the patient died six weeks later of intracranial haemorrhage.

Three comments are made on this case – two by psychiatrists, Dr K Davison and Dr Ashley Robin, the other by a professor of Christian ethics, Professor J C Blackie. Both psychiatrists argue that when a patient's mind is affected by mental or organic illness to the degree that 'he cannot bring a rational and conscious mind' to the question of his treatment then the doctor, in consultation with the relatives, making clear to them the likely course of events if an operation is not performed, must take whatever is the proper course of action, in this case surgery. In this view, such an operation performed immediately the diagnosis was confirmed might not have been so complicated. Professor Blackie, commending 'the attempt to regard the patient as a responsible human being' with a 'moral right to be consulted on all aspects of treatment', questions in this patient the limits to which the appeal to reason was carried. He concludes that 'in this situation the advice and consent of the family must weigh more heavily than the statements of the patient'.

A 59-year-old man was referred to a psychiatric hospital because his memory was fading and he felt he was being persecuted. He had been previously well, with no personal or family history of mental illness. He had married at 25, and had had a happy family life. At the time of admission his wife was still working and was living with him, while the two adult children lived nearby. Over the previous few months, however, his personality had begun to change. He had the fixed idea that he was being pursued by the police for some imagined crime, and that his family was planning to kill him. He slept poorly, ate little and could not concentrate on anything'. When seen by the psychiatrist he was restless, wearing an anxious expression, and kept wringing his hands and trying to leave the room. He was confused and depressed and was admitted to the ward under the diagnosis of presenile dementia with depression.

On the ward, formal psychological testing showed that his memory was severely impaired while he appeared to have an IQ within the normal range. This suggested diffuse brain damage, as did the EEG. A neurologist noted a large head and extensor plantar responses. The skull radiograph gave a vital clue: it showed an enlarged vault with a small posterior fossa, and suggested to the radiologist hydrocephalus as a result of aqueduct stenosis. He was transferred to a neurosurgical unit, where this diagnosis was confirmed by a lumbar air encephalogram and angiograms. Surgical correction of the hydrocephalus with a ventriculo-artrial shunt was the alternative to long inpatient care with declining mental function. When this was put plainly to the patient, however, he refused any operation on his head. On phenothiazine medication at this point he was less agitated and appeared to have good insight into his situation, in spite of the dementia. For several weeks he was pressed to consider the operation, but he insisted on returning home.

Initially at home he seemed stabilized, but on follow up a deteriorating picture emerged. He became suspicious again and his day-to-day activities diminished. Four months after discharge he became totally disorientated and needed admission under section 29 (72 hours only), which was then converted to section 25 (28 days only). (Both of these sections allow observation but certainly not operative treatment.) There was no objective evidence that the dementia had worsened, and although he was confused and initially unable to account for his actions the psychiatrists felt that he had retained insight and was aware that things were not what they had been when he was first admitted. He blamed this deterioration on the doctors: 'They gave me the mind of a baby'. He became more lucid and more understanding on phenothiazines, but continued to deny that he had a brain disorder and refused operation. Because of his retained insight the psychiatrists felt that they could not recommend him for operation against his expressed wish, especially as there seemed no clear indication as to how effective and safe the operation might be.

He was thus again discharged, and again followed up on phenothiazine drug treatment. On various

occasions doctors were able to persuade him to accept the operation, but he always changed his mind a few hours later. After 18 months he was admitted having taken an overdose of 100 aspirin tablets. His wife reported that he had been increasingly apathetic, forgetful and depressed. On this admission the patient was withdrawn, and his speech slow and monotonous. He had possible early optic atrophy and a hemiparesis. He denied that he had any brain abnormality, and declared that the operation had been devised as a punishment. Phenothiazines were stopped. He retained his paranoid ideas and guilt feelings and became increasingly drowsy. The psychiatrists now thought his objections to the operation could only be seen as part of the delusional system of the organic psychosis. He was therefore put on section 26 (for treatment) with the agreement of his family, and a valve was inserted at operation.

After this operation he became more lively but remained paranoid and kept trying to leave the ward. Six weeks after the operation he suddenly deteriorated and died of an intracranial haemorrhage. A postmortem examination revealed evidence of a subdural and subarachnoid haemorrhage, consequent on the operation. Hydrocephalus was confirmed, secondary to stenosis of the aqueduct.

Discussion

K DAVISON *Department of Psychological Medicine, Newcastle University*

CLINICAL ASPECTS

Diagnosis

Apart from the memory impairment the psychiatric features described are those of a psychotic depression with paranoid features which can, of course, coexist with organic brain disease. He is described as confused and depressed but no mention is made of his orientation in time and space so the meaning of the word 'confused' is not clear. As he was found to have an IQ in the normal range one assumes that he did not show clinical evidence of impaired conscious level or intellectual deterioration.

Severe memory impairment with preservation of intellect does not necessarily indicate diffuse brain damage; it is more likely to indicate localized damage in the region of the third ventricle or bilaterally in the temporal lobes.

The finding of skull enlargement both clinically and radiologically is rather puzzling. This would not be likely to occur in a 59-year-old man developing hydrocephalus for the first time. It suggests that the aqueduct stenosis and hydrocephalus, possibly arrested, were of much longer duration and had only recently begun to decompensate. Up to this point there were grounds for scepticism over the contribution of the hydrocephalus to his psychiatric presentation. However, the subsequent occurrence of a true confusional episode and the appearance of early optic atrophy and a hemiparesis indicate that slowly progressive organic brain disorder was present.

Treatment

Eventually it became clear that surgical intervention to relieve the hydrocephalus was necessary. Up to that point one would have liked to see more attention paid to the considerable depressive element in the psychiatric presentation – guilt, agitation and a suicidal attempt. The only medication mentioned is phenothiazines and it seems likely that a better initial response would have occurred with antidepressant therapy.

Outcome

It is unfortunate that the patient died six weeks after the operation. Without more information it is difficult to understand why intracranial haemorrhage after six weeks should be regarded as 'consequent on the operation'. Also it is not clear why his mental state showed little improvement after the operation. This could have been because the valve was not functioning, brain damage was too extensive or the psychiatric syndrome was independent of the brain disorder. Again more information is needed to distinguish between these possibilities.

ETHICAL ASPECTS

As indicated above this case was by no means clear-cut and the clinicians concerned can be forgiven for some hesitation in deciding on the best line of action.

Accepting the assumption that the basis of the psychiatric disturbance was the hydrocephalus it could be argued that an earlier recourse to operative treatment might have led to a more satisfactory outcome. The operation was delayed because of the patient's refusal and the psychiatrist's reluctance to compel him to undergo the operation against his will. It is stated that his insight was retained but this is difficult to accept in the face of statements that at other times he thought the police were after him, his family were planning to kill him, he was suspicious, confused and unable to account for his actions and he blamed the deterioration on his doctors.

The relevant parts of section 26 of the Mental Health Act are that he was suffering from a mental disorder and it was necessary 'in the interests of the patient's health or safety' that he be detained in hospital. The question of his degree of insight is therefore hardly relevant to the decision about applying section 26 as there was ample evidence of ongoing mental disorder which would soon have become even more apparent if phenothiazines had been discontinued. One suspects that the real doubt in the psychiatrists' minds was whether the brain

operation was really 'in the interests of the patient's health or safety'.

The ethical problem therefore is resolved into the question of how far one should go in persuading a patient and his relatives to have a form of treatment which is theoretically desirable but in practice unpredictable in outcome. In my view the most one can do is to outline the likely course of events if the operation is not performed and the risks involved if it is performed and let the patient decide. If, as in this case, the patient is incapable of a rational judgment because of mental disorder the decision should be made by the relatives.

ASHLEY ROBIN *Runwell Hospital, Wickford, Essex*

The history describes organically determined mental changes of a few months' duration in a previously stable man. Investigations conducted with a high degree of expertise rapidly revealed the cause of the condition to be hydrocephalus secondary to stenosis of the aqueduct. Nag and Falconer (1966) in a series of 10 such patients found four with impaired memory and seven with 'mental impairment', of whom 'only four complained'. After operation six of the seven with 'mental impairment' improved, although their illnesses were from one to 28 years' duration. The symptoms of the patient reported in this conference, it must be stressed, included not only impaired memory, impaired concentration, and confusion but also, as an integral part of the illness, delusions. In short, the patient's delusions were *caused by* a treatable disease. His first admission, we are told, was arranged informally (in the context of the Mental Health Act, 1959). When improved as far as agitation, and perhaps delusions, were concerned – if this is what is meant by 'good insight' – he refused operation, presumably having understood the facts of the operation. Four months later he was admitted 'for observation' under sections 29 and 25 of the Mental Health Act 1959 and at this point it is necessary to clarify the legal situation in this admission. In the first place such an admission required that the patient suffered 'from mental disorder of a nature or degree which warrants detention of the patient'. Such a degree, we are informed by the Memorandum on the Mental Health Act prepared by the Ministry of Health in 1960, 'will be taken as equivalent to the phrase "a person of unsound mind" which has been used hitherto' in the Lunacy Acts. Secondly, the 'detention of the patient in a hospital under observation' is according to the Act itself, 'with or without medical treatment' and 'in the interests of his own health or safety'. The Memorandum says quite explicitly: 'Section 25 makes it clear that the patient may receive treatment as well as being under observation'. Medical treatment may be of any sort and surgery is nowhere precluded in patients detained under the Mental Health Act. I therefore cannot accept the comments in this context presented in the case report.

In the second admission dementia is noted with, once again, delusions. While the delusions of the first admission, namely, that his family were trying to kill him, might be accepted as possibly relevant to his capacity to decide on surgery, his delusions during the second admission undoubtedly bore directly on this capacity. He believed first that his doctors, those advising him, had given him the mind of a baby, and one must accept that such an idea would colour his attitude to advice. Secondly, he believed that *he did not have brain disorder*. In the face of this idea it is difficult to understand the psychiatric conclusion that he had 'retained insight', and it would seem certain that he was deciding the issue of treatment *on the basis of delusions*. Such a conclusion was indeed reached 18 months later when further physical and mental deterioration had occurred. Unfortunately the operation proved to be complicated, and the patient's survival time was insufficient to permit the full assessment of any benefits that might have occurred in the uncomplicated procedure. The individual outcome is, however, irrelevant to the decision-making process which anticipated it, as it presumably could not have been predicted. The general prediction which would have been used would be derived from series like that quoted above, in which a high degree of success was achieved.

Psychiatric attitudes to neurosurgery may well be coloured by the trend to polarization which 'psychosurgery' on the intact brain has produced. 'Psychosurgery' is, however, hardly relevant in this case.

The medical ethic, I understand, requires the doctor to help the helpless. The unconscious patient cannot be asked for consent, and where delusions bear on the situation being considered, the patient cannot bring a rational and conscious mind to the question. Our patient here was acting like a millionaire, making a will in the belief that he had no money. In the case of the millionaire, however, one might rely on a previous decision taken with his full faculties. In other words, a previous will would stand. Should we accept the patient's last rational decision and ignore subsequent changes – either way? Should we ignore a *request* based on delusions as well as one refusing it. I think not. The patient's 'rational' decision was taken in a particular situation. His clinical condition changed – the facts to be considered changed – and the patient was unable to consider them. My own view would have been that operation was a proper course of action to treat a mental illness under the Mental Health Act at the time of the second admission. This case might demonstrate that, contrary to the views of Szasz (1957), the Mental Health Act is an ethical necessity, despite the

unhappy outcome, which might have occurred at any time.

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J C BLACKIE *University of Edinburgh*

The ethical dilemma in this case can be stated as the need to uphold the dignity of the patient in terms of seeking an appropriate response from him for surgical intervention, and the need to uphold the dignity of the medical profession in terms of the practice of appropriate treatment when the complaint is diagnosed.

This resolution of this dilemma is complicated by two factors. One concerns the ability of the patient to make a rational decision concerning the giving of permission to operate. This seems to be in doubt throughout the case history as presented. ('The psychiatrists now thought his objections to the operation could only be seen as part of the delusional system of his organic psychosis'.)

The second complication involves the imprecision of the diagnosis and consequent different types of treatment carried out. There seem to be differences of opinion between the neurologist and the psychiatrist concerning the origins of the patient's complaint. On the one hand the necessity of surgical intervention was advocated which would have given quick relief. On the other, chemotherapy was practised on several occasions over a period with a little success, but no lasting relief.

In the event, the patient's objections were overridden and his will to decide taken from him in terms of section 26 and an operation to the head was performed. The diagnosis remained imprecise at necropsy.

Two comments can be offered after the event. First, the attempt to regard the patient as a responsible human being whose moral right to be consulted on all aspects of treatment is both to be commended and questioned. It must be commended by a community which wishes to know everything about the treatment to which it will be subjected when in ill health. And the appeal to the will of the patient is undoubtedly accepted and applauded as a crucial element in any treatment programme. But the limits of this appeal need to be clearly defined. At what point is appeal to irrationality doing a disservice to a patient, and causing unhappiness to the family and exacerbation to the condition? It can be argued that this was the situation in this case.

Second, the conflict between surgery and chemotherapy is presented here as an 'either/or' situation. Doubtless each protagonist could advance compelling reasons for their methods and surgery still has the traditional ring of finality and crisis intervention about it, especially when it is performed on the head.

It is too easy to resolve the crisis by advocating the cooperation of both sides in an effort to ease the patient's complaint. In this case, efforts were clearly made to effect such a resolution, but the cooperation of the patient in this joint programme was denied. There may be times when the dignity of the patient can be advanced by recourse to surgery even though the patient will not consent and the other consultants have reservations about its effectiveness. In this situation the advice and consent of the family must weigh more heavily than the statements of the patient.